

Original Article

The Consequences of Child's Congenital Heart Disease for Parents: A Qualitative Study

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ABSTRACT

Background: Affliction of a child by a chronic disease can significantly affect the whole family. Identifying the consequences of a child's congenital heart disease (CHD) for parents can help health-care providers provide better care services to them. **Objectives:** This study aimed at exploring the consequences of a child's CHD for parents. **Methods:** This study was conducted in 2020 using conventional content analysis. The 30 parents of 15 children afflicted with CHD were purposively recruited from a hospital and a physician's private office in Sanandaj, Iran. Data were collected via semi-structured interviews and continued up to data saturation. Data analysis was performed via conventional content analysis suggested by Graneheim and Lundman. **Results:** The consequences of a child's CHD for parents were grouped into three main categories, namely threatened family integrity (with three subcategories), psychological turmoil (with five subcategories), and being in limbo (with three subcategories). The 11 subcategories of these three categories were the effects of CHD on parents, neglectful parenting for other family children, reluctance to have another child, anxiety, maternal depression and somatization, helplessness, fear over treatment failure, acceptance of an unchangeable reality, uncertain future, concern over hiding or not hiding a child's CHD, and a heart full of pain, respectively. **Conclusion:** A child's CHD can threaten family integrity, cause parents psychological turmoil, and put them in limbo. Health-care providers, particularly nurses, need to assess the needs of these parents and provide them with professional counseling and need-based emotional, informational, and financial support in order to reduce the negative effects of CHD on them.

KEYWORDS: Child, Congenital heart disease, Parents, Qualitative research

INTRODUCTION

Childbirth is one of the most striking life experiences, and it is mostly associated with parental happiness.^[1] However, it can cause serious emotional and mental distress if the child is born with congenital heart disease (CHD) that needs surgical correction or leads to disability or death.^[2]

CHD is a structural defect of the heart and the great vessels that can lead to significant functional impairment.^[3] Each year, 10,000 children per one million live births are born with CHD in Iran.^[4] The symptoms of CHD in the afflicted child cause great

tension and anxiety for parents and hence, accepting parental roles for a child with CHD is associated with various physical, psychological, and socioeconomic challenges and problems for parents.^[1] Examples of these challenge and problems include anxiety, somatization,^[5] distress, withdrawal from peer activities, stress, and

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uncertainty.^[6-8] The severity of parental problems largely depends on the severity of CHD symptoms^[3,9] and the characteristics of the immediate sociocultural background. The guideline of the National Institute for Health and Care highlights that the parents of children afflicted with CHD may need help and support to cope with their problems.^[2]

The review of the existing literature revealed that most studies into the consequences of CHD were conducted using quantitative designs. These designs do not usually provide detailed data about parental experiences^[10] and mostly address limited variables such as distress, hopelessness, and quality of life.^[2,9] Qualitative studies in this area were also conducted either on patients or only on mothers rather than both parents or addressed a particular stage of life such as childhood, adolescence, or adulthood.^[11,12] Moreover, most studies into CHD-related parental problems were conducted in countries that differ from Iran, with respect to their sociocultural background, economic status, health-care system, diagnostic and treatment facilities, and abortion-related beliefs.^[3,11,13] Therefore, their findings are not easily generalizable to the context of Iran. Consequently, there is a wide knowledge gap regarding the experiences of the parents of children with CHD. The present study was designed and conducted to narrow this gap.

Objectives

This study aimed at exploring the consequences of a child's CHD for parents.

METHODS

Study design and participants

As part of a larger research project, this study was conducted in 2020 using conventional content analysis. This approach is one of the most important approaches to qualitative description that helps delve into human experiences.

The participants were both parents of 15 children with CHD (i.e., 15 fathers and 15 mothers). They were purposively recruited from the private office of a cardiologist in Sanandaj, Iran as well as a hospital affiliated to Kurdistan University of Medical Sciences, Sanandaj, Iran. Inclusion criteria were agreement for participation and having a child aged younger than 12 years with cyanotic or non-cyanotic CHD and no other congenital abnormalities (such as Down syndrome or cleft lip). Sampling was performed with maximum variation regarding parents' educational level and children's gender and age.

Data collection

Data were collected through personal semi-structured interviews. Interviews were held using an interview guide

with general open-ended questions, such as "Could you tell a little about your child's illness and how you were informed about it?" "Could you tell me what happened to you and to your life after you were informed about your child's disease?" Moreover, participants were asked to provide more explanations about their experiences using probing questions, such as "Would you please explain more about this?" Interviews were conducted at participants' preferred time and place and lasted 30–95 min with a mean of 45 min. All interviews were conducted by the fourth author in Persian and were audio-recorded using a digital recorder. Data collection was continued up to data saturation, which was achieved when no new data were obtained from the interviews.

Data analysis

Each interview was immediately typed word by word and analyzed using the conventional content analysis approach suggested by Graneheim and Lundman. The interview transcript was frequently read to gain a general understanding about its content. Then, meaning units were identified, condensed, abstracted, and coded. The codes were compared with each other^[14] and grouped into subcategories and categories according to their similarities. The MAXQDA software was used for data management. Table 1 shows an example of data analysis.

Ethical considerations

The Ethics Committee of Tehran University of Medical Sciences, Tehran, Iran, approved this study (code: IR.TUMS.FNM.REC.1397.166). Participation was voluntary, and participants could withdraw from the study at will. Written informed consent was obtained from all participants. Data were kept confidential throughout the study.

Trustworthiness

Trustworthiness was established using the five criteria proposed by Lincoln and Guba, namely credibility, dependability, confirmability, transferability, and authenticity.^[15] Credibility was maintained via prolonged engagement with the data, close relationship with participants, collection of reliable data, and peer debriefing. Dependability and confirmability were ensured using peer checking by coauthors. Detailed descriptions of the study context were provided to ensure transferability. Moreover, authenticity was maintained through close collaboration between the interviewer and participants and their bilateral agreement on the regulations of the study.

RESULTS

In total, 30 parents of 15 children afflicted with CHD were interviewed. The mean of participants' age was

Table 1: An example of data analysis

Subcategory	Primary codes	Quotations
Neglectful parenting for other family children	Parents' greater attention to the child afflicted with CHD	I pay more attention to him than my other children
	Social isolation of the child afflicted with CHD	I see my nephew gets tired. He is isolated because he was looked after a lot and did not engage in social activities.
	Parental negligence toward other children of the family	When we were in hospital for my son's surgery, my daughter went to elementary school. My mother-in-law had taken her to school. She still complains that on the first day of school, parents had taken their children to school but my parents were absent (P. 15).

28 ± 6.54 years. Participants' children were seven girls and eight boys with an age range of eight days to 11.5 years. Table 2 shows participants' demographic characteristics.

Data analysis resulted in the development of 1,248 primary codes, 11 subcategories, and three main categories. The three main categories of the study were threatened family integrity, psychological turmoil, and being in limbo [Table 3].

Threatened family integrity

This category consisted of three subcategories, namely the effects of CHD on parents, neglectful parenting for other family children, and reluctance to have another child.

The effects of CHD on parents

A child's CHD significantly affects different aspects of parents' lives and causes them different problems, such as marital breakdown, unhappy family atmosphere, and economic problems. Although most parents reported that a child's CHD negatively affected their relationships, some of them reported that a child's CHD required them to strengthen their marital relationships in order to overcome CHD-related problems.

At that time, I did not look after my house and my husband. We had forgotten our marital relationships and just thought about our son (P. 11).

Physical and mental exhaustion was another negative effect of a child's CHD on parents. The CHD-associated grief and suffering had made participants worn out and exhausted in the eyes of others.

I had grieved so much that I looked older. My front hair got completely white during the month that my child was in hospital (P. 19).

According to the participants, a child's CHD makes parents isolated, causes them to cry a lot, and hence, makes the family atmosphere very unhappy.

My child's disease is in my mind all the time. Happiness has left our life (P. 10).

The parents of children afflicted with CHD also experience heavy financial strain due to frequent medical visits, echocardiography, surgeries, medications, and transportations to health-care settings. Participants reported that much of their income was spent on their children's CHD. Financial strains had also required fathers to work in a second job, mostly as a laborer.

Our financial status is not good. We live in a rented house. My girl underwent another surgery while my husband was then unemployed at that time and we couldn't pay for insurance (P. 23).

Neglectful parenting for other family children

All participants, particularly mothers, reported that they paid greater attention to their child afflicted with CHD.

I pay more attention to him than my other children (P. 13).

The excessive attention of parents and relatives to children afflicted with CHD makes them socially isolated. A mother whose niece was also afflicted with CHD said,

I see that my niece is bored, gets tired soon, and is not sociable probably because they look after him very much and he has not been part of a society and with other children (P. 13).

The experiences of some participants showed that their healthy children were dissatisfied with their parents' greater attention and kindness for their sibling afflicted with CHD, spending limited time for them, and having limited social interactions.

When we were in hospital for my son's surgery, my daughter went to elementary school. My

Table 2: Participants' characteristics

Participants' no.	Parents' no.	Gender	Age (years)	Child's age	Diagnosis	Duration of CHD diagnosis
1	1	Female	22	8 days	PDA	8 days
	2	Male	25	8 days	PDA	8 days
2	3	Female	20	6 months	VSD	5 months
	4	Male	26	6 months	VSD	5 months
3	5	Female	38	18 months	PA	16 month
	6	Male	40	18 months	PA	16 month
4	7	Female	35	16 months	PDA, PFO	14 month
	8	Male	34	16 months	PDA, PFO	14 month
5	9	Female	30	40 days	PDA, VSD	40 days
	10	Male	36	40 days	PDA, VSD	40 days
6	11	Female	18	11 years	VSD	10 years
	12	Male	23	11 years	VSD	10 years
7	13	Female	28	20 days	PFO	20 days
	14	Male	38	20 days	PFO	20 days
8	15	Female	30	10 years	VSD	9 years
	16	Male	31	10 years	VSD	9 years
9	17	Female	38	5 years	VSD	5 years
	18	Male	39	5 years	VSD	5 years
10	19	Female	30	6 years	VSD	6 years
	20	Male	30	6 years	VSD	6 years
11	21	Female	25	3 years	VSD, ASD	2 years
	22	Male	25	3 years	VSD, ASD	2 years
12	23	Female	20	1.5 years	PDA	1.5 years
	24	Male	22	1.5 years	PDA	1.5 years
13	25	Female	21	5 years	PDA	5 years
	26	Male	22	5 years	PDA	5 years
14	27	Female	23	8 years	VSD	8 years
	28	Male	24	8 years	VSD	8 years
15	29	Female	20	6 years	ASD	6 years
	30	Male	27	6 years	ASD	6 years

VSD: ventricular septal defect, PDA: patent ductus arteriosus, ASD: atrial septal defect, PA: pulmonary atresia, PFO: patent foramen ovale

Table 3: The consequences of a child's CHD for parents

Categories	Subcategories
Threatened family integrity	The effects of CHD on parents Neglectful parenting for other children of the family Reluctance to have another child
Psychological turmoil	Anxiety Maternal depression and somatization Helplessness Fear over treatment failure Acceptance of an unchangeable reality
Being in limbo	Uncertain future Concern over hiding or not hiding a child's CHD A heart full of pain

mother-in-law had taken her to school. My daughter still complains that in the first day of school, parents took their children to school but my parents were absent (P. 15).

Some participants noted that other children in the family financially and emotionally supported their parents and participated in child care.

My two other children are all concerned about helping their sick sibling. I used to give my eldest son some pocket money. At the time of each monthly medical visit of my sick son, the eldest son said that he also had some money for the visit and noted that he had saved his pocket money for the visit (P. 27).

Reluctance to have another child

Almost all participants acknowledged that they would have opted for abortion if they had been informed of their child's CHD during pregnancy. Moreover, they reported reluctance to have another child due to feeling tired with the problems associated with having a child afflicted with CHD. Consequently, they had undergone tubal ligation in order to prevent any more pregnancies or reported resorting to abortion in case of pregnancy.

I had tubal ligation in order not to have any other child (P. 15).

On the other hand, some participants had decided on another pregnancy without receiving any screening intervention due to having limited knowledge about the possibility of their newborn's CHD in any new pregnancy.

After my child who is afflicted by CHD, I gave birth to two children and both of them are healthy. Of course, I didn't know that screening is essential for CHD (P. 19).

Psychological turmoil

Unsuccessful CHD treatments may lead to great anxiety and psychological turmoil for parents. The five subcategories of this category were anxiety, maternal depression and somatization, helplessness, fear over treatment failure, and acceptance of an unchangeable reality.

Anxiety

Parents were greatly concerned about any need for surgery in the future, failure of surgery, their children's inability to perform some activities, and their children's growth retardation.

I have great fear over being told in the next medical visit that my child needs a surgery (P. 18).

Maternal depression and somatization

Mothers had to spend more time with their children afflicted with CHD. Consequently, CHD-induced stress had caused some of them different problems such as depression and somatization.

When the doctor told me that my child had heart problem, I experienced so severe [psychological]

problems that they took me to psychologists. They gave me counseling and medications; but I didn't use the medications (P. 13).

Helplessness

Great concern with a child's CHD had reduced the ability to make appropriate treatment-related decisions among some parents. Parents often referred to different doctors who provided them with different treatment options.

My wife was so upset that she couldn't decide whether to hospitalize our child in this hospital or take him to a better-equipped center" (P. 28).

Fear over treatment failure

The most important source of concern for participants was fear over treatment failure and subsequent loss of their children. A couple, both of whom were nurses, with a child afflicted with CHD having undergone cardiopulmonary resuscitation said,

We experienced great stress during resuscitation. I was deeply concerned over the possibility of hypoxia during resuscitation (P. 30).

Acceptance of an unchangeable reality

The parents of children with CHD usually oscillate between a sense of self-deception and a sense of realism. They may attempt to convince themselves that their child may never recover but resist accepting this reality.

The last time I took my child to doctor, we expected to be told that the surgery is necessary. I felt like I have been given the whole universe when they said that my child didn't need surgery due to the formation of a thin membrane in the defective area. Now that I want to take him again to doctor, I don't want to give myself any hope (P. 21).

Being in limbo

The third main category of the consequences of a child's CHD for parents was to be in limbo. This main category consisted of three subcategories, namely uncertain future, concern over hiding or not hiding a child's CHD, and a heart full of pain.

Uncertain future

Participants were worried about their children's future and the effects of CHD on it. Uncertainties about their children's future caused them great stress and placed them in limbo. They attempted to hide their children's illness from others in order to prevent the potential

social effects of the disease on the different aspects of their children's lives, such as marriage.

I hide my son's disease because I think with myself that if he falls in love with his cousin, his uncle may disagree with their marriage due to my son's disease (P. 20).

Moreover, participants attempted to hide their children's disease in order to prevent others from ridiculing their children.

We never told others about our child's disease because I was concerned with the fact that during any play, the children of my relatives might foolishly tell him about his heart problem (P. 22).

Concern over hiding or not hiding a child's CHD

Some participants believed that hiding their children's disease was not necessary and had no problem with telling others about it, whereas most of them wanted to hide their children's disease due to their fear over the possible consequences of not hiding it. Nonetheless, CHD symptoms were so severe in some cases that hiding CHD was impossible.

Even at my dad's house, I didn't let anybody see me when I gave him his drugs (P. 21).

Some participating fathers whose children did not suffer from significant physical symptoms of CHD had hidden the illness even from their wives for a while in order not to cause them undue stress.

My husband didn't tell me my child had CHD until I saw in my child's medical records the diagnosis of PFO [i.e., patent foramen ovale] (P.9).

Some parents also attempted to hide CHD from their own children afflicted with CHD in order to protect them against the negative effects of CHD diagnosis on their morale, mood, and self-esteem.

My child's hand had been broken months before we took him to angiography. I told him we are going to take a hand radiography (P. 16).

A heart full of pain

The annoying reactions, words, looks, and curiosity of others regarding a child's CHD were the other factors causing participants to feel being in limbo. Participants whose children afflicted with CHD were female were extremely concerned with the negative effects of possible surgeries on their daughters' physical beauty and the chance of marriage.

The opening of my daughter's chest during surgery can negatively affect her beauty. I'm very concerned

about this because this is considered as a defect in our context (P. 22).

Participants reported that some people said that their child would die very soon and some considered them unable to bear a healthy child. Such annoying words and reactions made participants very anxious.

One night, our guest had told my wife she was scared of hugging my child. My wife cried a lot that night (P. 24).

Others' curiosity about a child's symptoms and the characteristics of CHD also caused suffering for participants.

My child always cried. When we had a guest, they called us after going to their home in order to ensure that my son hadn't died of crying and shortness of breath. They called us several times to know what happened and what we did (P.11).

DISCUSSION

This study explored the consequences of a child's CHD for parents. Findings showed that a child's CHD has many different consequences for parents, which were categorized into three main categories, namely threatened family integrity, psychological turmoil, and a state of being in limbo. These consequences affect not only parents but also other children of the family.

Study findings showed that a child's CHD can affect parents' marital relationships and make the family atmosphere unhappy. The results of previous studies into the consequences of a child's CHD for parents are inconsistent. For example, a study showed that a child's CHD negatively affected parents and caused them physical and psychological stress as well as a sense of guilt and discomfort.^[12] Contrarily, another study found that having a child afflicted with CHD did not affect marital satisfaction^[2] and a study revealed that having a child afflicted with CHD strengthens parents' marital relationships.^[16] The severity of the effects of a child's CHD on parents varies according to the immediate conditions. For instance, a study reported that divorce rate among the parents of children afflicted with CHD depended on CHD type and severity.^[17]

We also found that parents' close attention to their children afflicted with CHD and restriction of their social activities had made them socially isolated and deprived other children from parents' close attention. Previous studies reported that children afflicted with CHD were concerned with their parents' overprotection as well as the limitations of their social activities.

For example, in a study, children afflicted with CHD reported that their mothers kept them under constant supervision and treated them like a small kid.^[18] Parental close supervision and attention for children afflicted with CHD make them alone and isolated, reduce their ability to make friends, and hence, may require them not to tell their friends about their problems and hide surgical scars on their chest from them.^[19]

Study findings also indicated that CHD affliction of a child considerably affects parents' willingness to have more children. Almost all participants noted that they would have performed abortion if they had been informed about CHD during pregnancy. Moreover, they were reluctant to have another pregnancy due to their fear over giving birth to another child afflicted with CHD. Meanwhile, some parents were unaware of the possibility of CHD in the next pregnancies since they had received limited education from health-care providers and hence, had given birth to new children after having a child afflicted with CHD. Evidence shows that the definite diagnosis of CHD during pregnancy is associated with a greater likelihood of pregnancy termination and a lower rate of neonatal mortality.^[20]

Participants also reported psychological turmoil due to their anxiety, helplessness, likelihood of a child's death, fear over inability to care for other children, fear over treatment failure, and a necessity to accept the unchangeable reality of CHD. These problems had caused them a state of constant restlessness. In line with our findings, a former study reported fear over losing the child afflicted with CHD as one of the most important concerns of parents.^[2] Another study showed that additional and unusual physical care needs of these children lead to psychological distress and emotional problems for mothers.^[21] Moreover, a study showed that the parents of children afflicted with CHD experienced high levels of stress irrespective of CHD severity and noted that these parents were more likely to experience doubts and stress regarding their parental competence.^[17]

Study findings also revealed that a child's CHD places parents in limbo, denoting that these parents experience suffering due to their perceived inability to do anything for their children afflicted with CHD. Participants were concerned about their children's uncertain future, hiding or not hiding their children's disease from others, and the negative effects of corrective surgeries for CHD on the physical beauty of their children, particularly their daughters. In line with this finding, a former study found that both children afflicted with CHD and their parents were concerned about their future and the effects of CHD on their long-term health.^[18]

Most of our participants tended to hide their children's CHD due to their fear over ridiculing their children by peers, losing marriage opportunities for their children, and annoying looks of others toward their children. Similarly, in a former study, children afflicted with CHD also reported that their peers ridiculed them by calling them blue-lip or purple-lip.^[18] In another study, girls with CHD were also worried about being unable to wear strappy clothes due to the possibility of exposing the surgical scar on their chest and being ridiculed by others. Some of them also reported that they felt bad feelings when their friends curiously looked at their scar while they changed their clothes in the school locker room.^[22]

This study provided detailed information about the experiences of parents with children afflicted with CHD. One of the main limitations of the present study was the limited accessibility of eligible parents in public health-care settings, which required us to sample not only from a public hospital but also from the private office of a cardiologist.

CONCLUSION

This study highlights that a child's CHD can threaten family integration, cause parents psychological turmoil, and give them a feeling of being in limbo. Health-care providers, particularly nurses, need to employ strategies to carefully assess these parents' needs, provide them with professional counseling, and provide them with need-based emotional, informational, and financial support in order to reduce the negative effects of CHD on them. Further exploration of the consequences of a child's CHD on parents is recommended through interviewing parents, children afflicted with CHD, and other children of the families.

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Conflict of interest

There are no conflicts of interest.

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